



Data Report 2016

Early Hearing Detection and Intervention



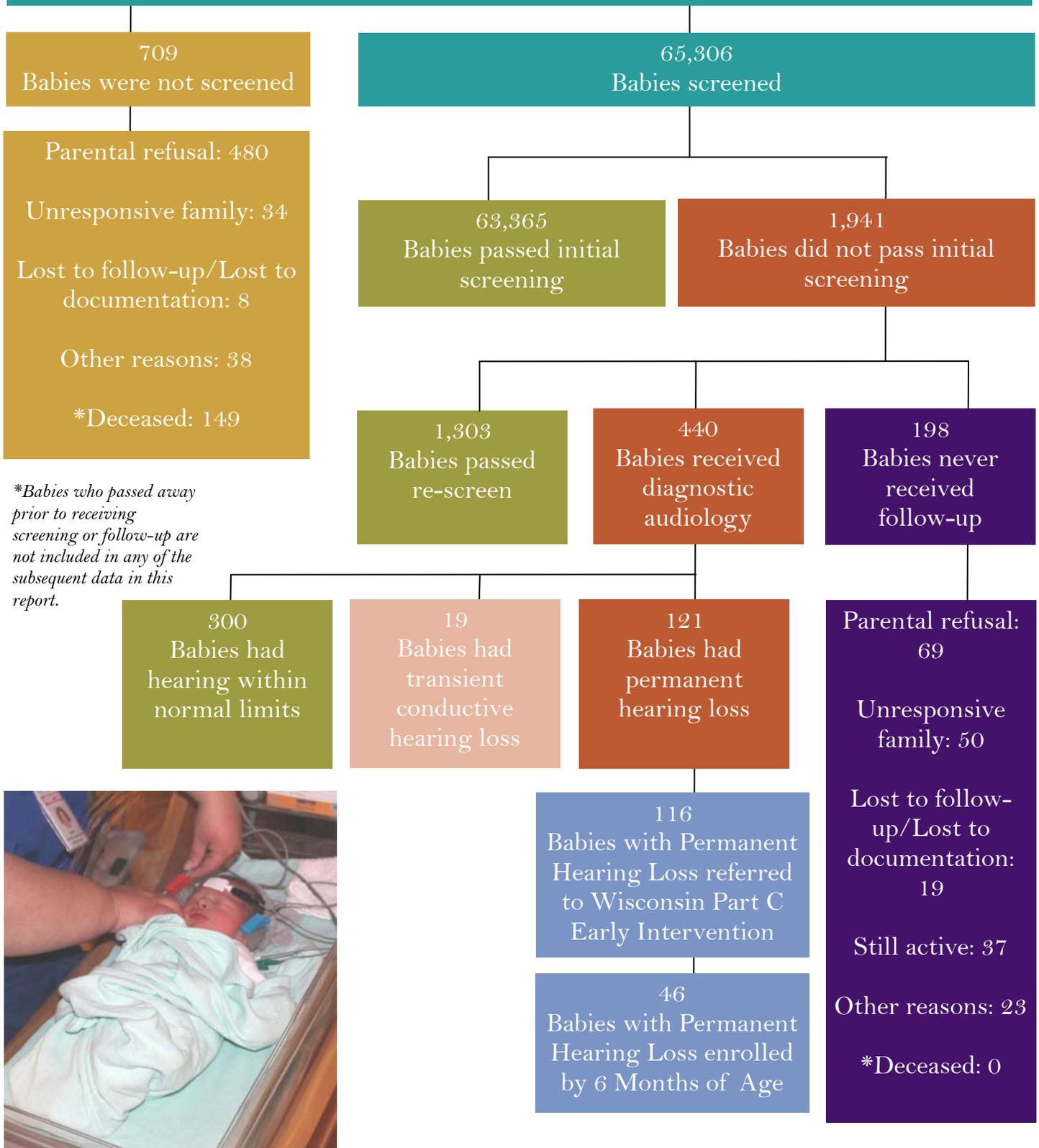
Wisconsin Sound Beginnings
Fall 2017

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Screening, Follow-up, Diagnosis, and Early Intervention Flowchart

66,015 newborn hearing screening records in Wisconsin's data system for babies born in 2016





Introduction

Wisconsin Sound Beginnings is the state's Early Hearing Detection and Intervention (EHDI) program. Sound Beginnings and partners, including hospitals, midwives, traditional birth attendants, audiologists, public health, primary care providers, and families, are all part of the EHDI system. Sound Beginnings serves as a safety net, monitoring its data and providing support and services throughout screening, diagnosis and early intervention. Sound Beginnings supports the EHDI system to increase the number of babies screened, reduce the percentage of babies not receiving follow-up (lost to follow-up or LTFU), increase the percentage of babies receiving timely diagnosis of permanent hearing loss, and increase the percentage of babies enrolling in early intervention.

Sound Beginnings and partners work together to strengthen the EHDI system; increase use of proven quality improvement strategies among hospitals and audiology clinics; increase local capacity for hearing screening for families unable to access traditional care; improve timely and accurate data entry into the WE-TRAC (Wisconsin EHDI Tracking, Referral and Coordination) data system; expand and sustain collaboration with statewide partners; and use sound data and continuous evaluation to inform decisions.

Sound Beginnings' efforts are designed to help Wisconsin meet the Joint Committee on Infant Hearing recommendations that babies are **Screened by 1 Month of Age**, **Diagnosed by 3 Months of Age**, and **Enrolled in Early Intervention by 6 Months of Age**.

Wisconsin EHDI 2016 Highlights

- Hospitals, midwives, public health, Sound Beginnings, and partners screened 99% of babies born in Wisconsin, with 98% screened by **1 Month of Age**.
- Midwives, public health, Sound Beginnings, and partners screened the greatest number of babies born out of hospital (1,240) to date.
- Audiologists diagnosed the highest percentage of babies with Permanent Hearing Loss by **3 Months of Age** (54%) to date.
- The highest percentage of babies with Permanent Hearing Loss were enrolled in Part C Early Intervention by **6 Months of Age** (37%).
- Sound Beginnings provided LTFU prevention outreach to 521 cases of babies who did not pass their hearing screening and were at-risk for being lost to follow-up.
- Sound Beginnings provided quality improvement and/or training and technical support to five hospital birthing units and three audiology clinics.
- Sound Beginnings provided 135 in-home or in-community screenings for babies who otherwise might not have received screening and/or follow-up.
- Sound Beginnings provided specialized early intervention support to 66 families with children who are deaf or hard of hearing and the Part C Early Intervention providers serving them.



Data for this report were calculated in August and September 2017. The data were generated primarily using the WE-TRAC data system. WE-TRAC allows Wisconsin providers to enter hearing screening, diagnostic audiology information, and Early Intervention referrals. WE-TRAC also receives information through an automatic process with Wisconsin's Part C Early Intervention data system, providing Early Intervention enrollment data. Sound Beginnings monitors, manages, and measures hearing screening, loss to follow-up, diagnosis and Early Intervention through WE-TRAC.



Wisconsin Sound Beginnings—Meeting the Department of Health Services’ Mission and Vision

Mission

To protect and promote the health and safety of the people of Wisconsin. Wisconsin Sound Beginnings accomplishes this by:

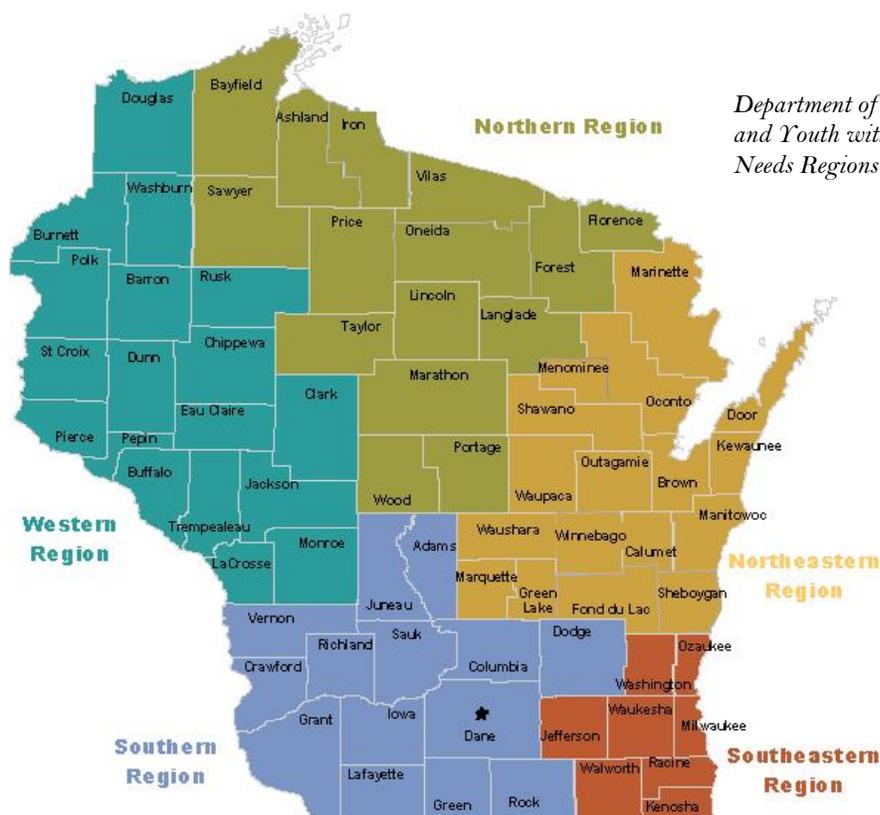
- **Identifying babies with hearing loss**—working as a team to increase the number of Wisconsin infants who are screened and receive timely, individualized follow-up care.
- **Increasing access to hearing-related services**—nurturing existing collaborations and forging new ones, and providing innovative outreach and nonbiased education to families, health care providers, and community partners.
- **Advancing early hearing detection and quality interventions**—providing children the opportunity to develop communication skills, cognitive abilities, and social-emotional well-being.

Vision

Everyone living their best life. Wisconsin Sound Beginnings’ vision is that all families will have equitable access to a seamless system of early and continuous hearing screening, skilled and timely diagnostics, and quality interventions to enable children who are deaf or hard of hearing to thrive.

The Wisconsin Sound Beginnings Statewide Team

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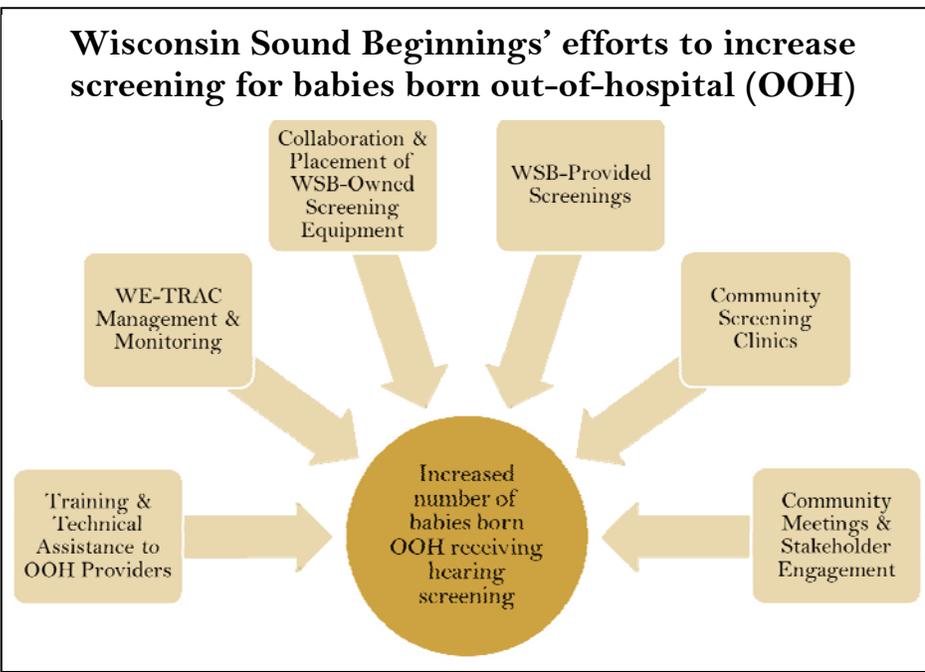


Department of Health Services Children and Youth with Special Health Care Needs Regions

Wisconsin Sound Beginnings is administered collaboratively through contracts between the Department of Health Services and the University of Wisconsin-Madison Waisman Center University Center for Excellence in Developmental Disabilities, Wisconsin State Laboratory of Hygiene, Chippewa County Health Department, and the City of Milwaukee Health Department.



Screened by 1 Month: *Reducing the Number of Babies Never Screened*

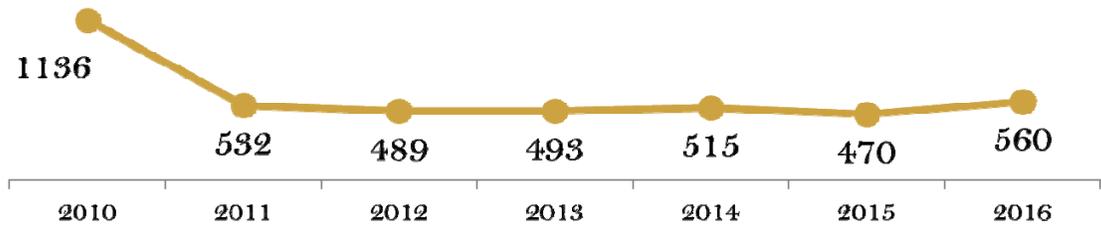


Each year, 99% of babies born in Wisconsin are screened for hearing loss; 98% are screened by **1 Month of Age**. Sound Beginnings' efforts to increase hearing screening target the less than 1% of babies born each year who do not receive hearing screening ("never screened").

Out-of-hospital births consistently account for the majority of babies never screened. In 2016, 79% of babies never screened were born at home or a freestanding birth center.

Sound Beginnings directs its efforts to Plain Communities (Amish or Mennonite) and families choosing an out-of-hospital delivery. Sound

Beginnings and partners work to ensure all families choosing an out-of-hospital birth who want newborn screening have access to it. Sound Beginnings provided 75 hearing screenings to babies born out-of-hospital in 2016—52 initial screenings and 23 follow-up screenings.



The Number of Babies Never Screened by Year of Birth



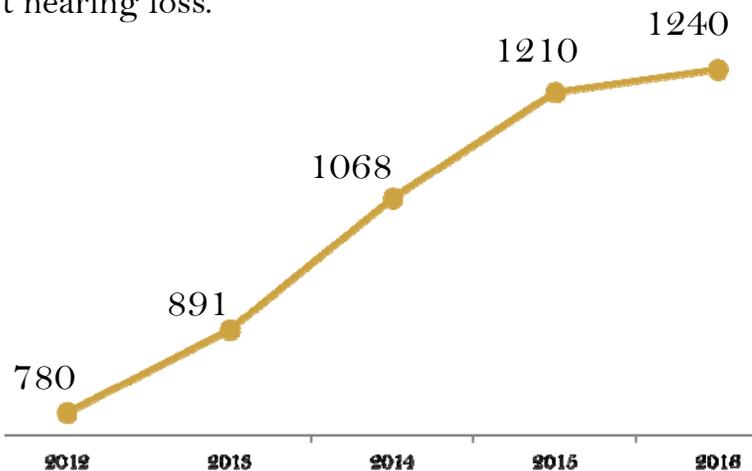
Sound Beginnings-provided initial screenings accounted for 4% of the total number of out-of-hospital babies receiving screening. Sound Beginnings and partners also held a screening clinic in Augusta to support Amish families in need of screening and/or diagnostic audiology.

Parental refusal continues to be the main reason a baby does not receive newborn hearing screening (86% of babies born in 2016 were not screened due to parental refusal). While honoring a family’s right to decline screening, Sound Beginnings and partners provide education and outreach about the value of newborn screening with key

74%

of babies born out-of-hospital were screened in 2016

stakeholders throughout Wisconsin. Sound Beginnings’ efforts to both provide and support culturally appropriate care for the Plain Community and families choosing an out-of-hospital birth successfully increased the number of babies screened. In 2016, 74% of babies born out-of-hospital were screened for hearing loss compared to 25% in 2011. In 2016, 1,240 babies born out-of-hospital were screened—the most to date. Since 2012, eight babies born out-of-hospital have been diagnosed with permanent hearing loss.



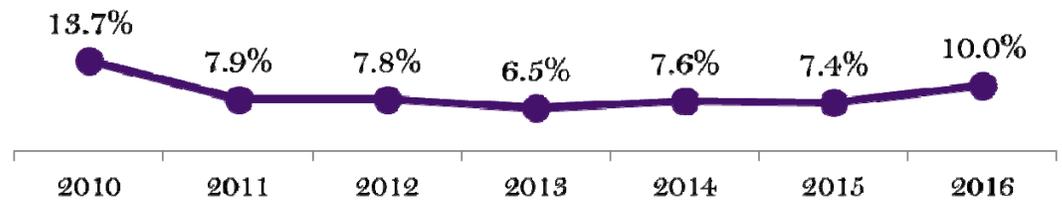
Number of Babies Born OOH Receiving Newborn Hearing Screening by Year of Birth



Diagnosed by 3 Months: *Reducing Loss to Follow-Up for Babies Who Did Not Pass*

Wisconsin successfully screens 99% of babies. Of the babies receiving screening, 3% statewide on average do not pass their initial screening. Babies who do not pass should go on to receive appropriate follow-up, including re-screening and/or diagnostic audiology. Cases of babies who did not pass and never received follow-up are considered “lost to follow-up” (LTFU) or “closed as incomplete.” To reduce LTFU and increase the number of babies receiving timely and appropriate follow-up, Sound Beginnings conducts baby- and organization-level outreach.

Wisconsin’s efforts, which began in 2011, successfully reduced Wisconsin’s LTFU rate.

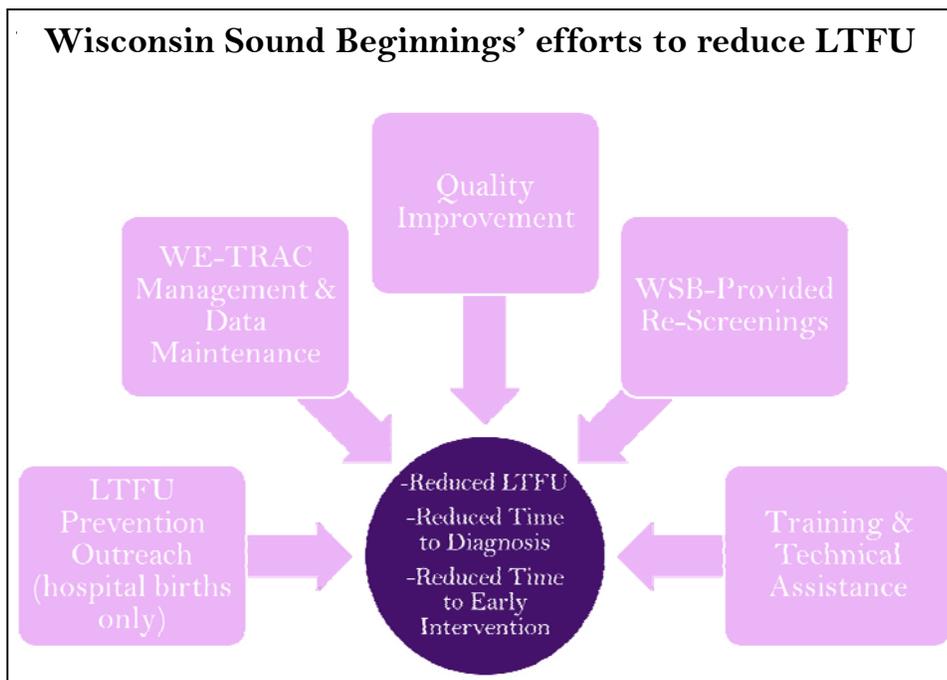


Percentage of Babies Who Did Not Pass Initial Screening and Did Not Receive Follow-Up (“LTFU Rate”) by Year of Birth

Each of Sound Beginnings' efforts contribute to Wisconsin's reduced LTFU rate.

In 2016, 30% (521 babies) of hospital-born babies who did not pass their hearing screening received LTFU prevention outreach. For each case, Sound Beginnings provided varying levels of outreach to hospitals, audiology clinics, primary care providers, and/or families.

As part of overall efforts to increase follow-up, Sound Beginnings spoke with more than 100 families with babies who did not pass and were at risk for LTFU. Sound Beginnings spoke with the families to address barriers to care and answer any questions regarding the follow-up process.



83

babies who did not pass received a Sound Beginnings-provided re-screen

Sound Beginnings also provided in-home or in-community re-screenings to 83 babies whose families were unable or unwilling to access traditional health care for follow-up. Sound Beginnings re-screened 4% of babies who did not pass their initial screening.

high LTFU, high percentage of babies who did not pass, or high levels of Sound Beginnings intervention.

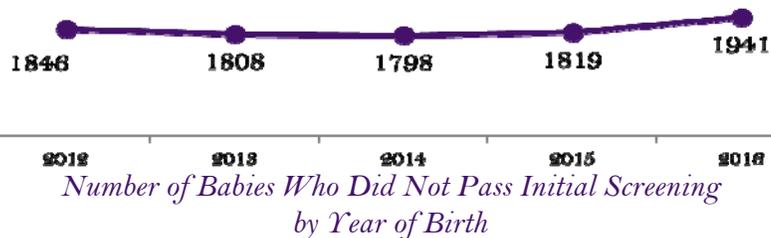
In 2016, Sound Beginnings collaborated with five hospital birthing units and three audiology clinics. These targeted efforts supported each of the organizations' increased knowledge and use of proven strategies to reduce LTFU.



Data Spotlight on LTFU

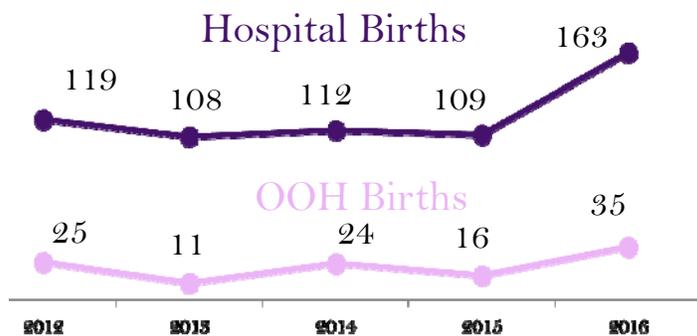
In 2016, Wisconsin's LTFU rate increased to 10%. This is a change from the last five years. To identify potential reasons why this rate increased, Sound Beginnings took a closer look at the data. Several factors could have potentially impacted LTFU:

- The number of babies who did not pass their initial screening increased.
- Out-of-hospital births accounted for 2.5% of Wisconsin births in WE-TRAC, the highest percentage to date. More babies born out-of-hospital received initial screening in 2016 than years prior.
- The number of babies who did not pass and did not receive follow-up due to parental refusal increased from 39 in 2015 to 69 in 2016.

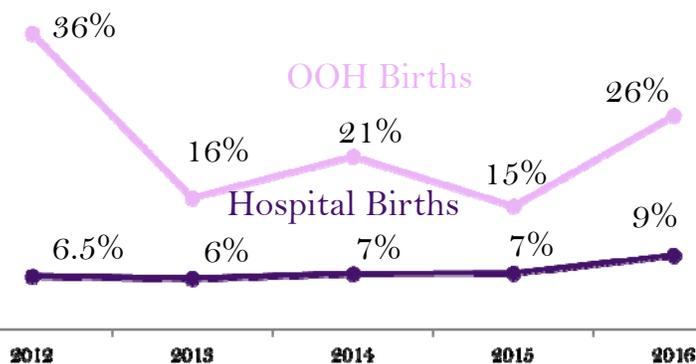


Despite the number of births decreasing in recent years (according to WE-TRAC), the number of babies who did not pass their initial screening increased between 2015 and 2016. In fact, 2016 had the most babies who did not pass their initial screening since 2012.

The number of babies born out-of-hospital who received hearing screening was the most to date in 2016 with 1,240 babies receiving hearing screening. In 2016, 35 babies born out-of-hospital did not pass and did not receive follow-up. The number of babies born at a hospital who did not pass and did not receive follow-up also increased in 2016.



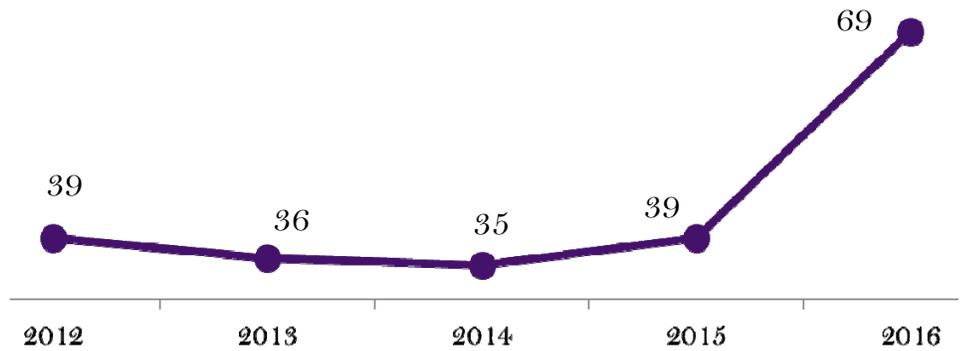
Number of Babies by Year and Place of Birth Who Did Not Pass and Did Not Receive Follow-Up



LTFU Rate for Babies Born Out of Hospital (OOH) and Hospital by Year of Birth

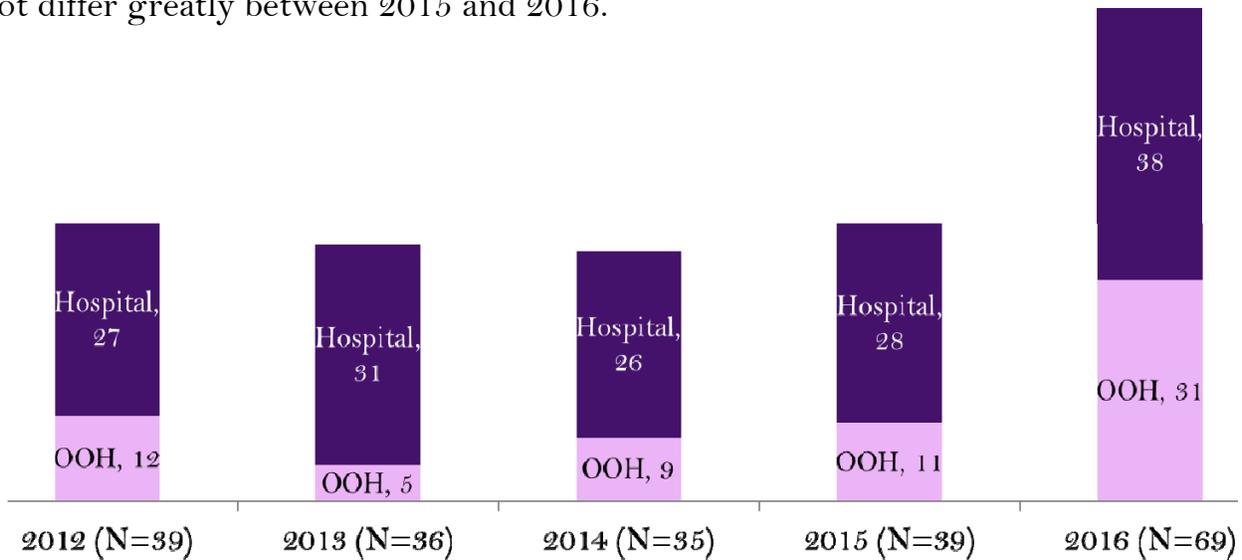
Sound Beginnings examined the LTFU rate for out-of-hospital births and hospital births. The percentage of out-of-hospital babies who did not pass and did not receive follow-up varied. The LTFU rate for hospital-born babies more closely parallels the overall LTFU rate.

Cases closed as incomplete in WE-TRAC, meaning the baby did not receive follow-up (in this case after not passing a hearing screening) may be closed under several categories, the definitions of which are guided by the Centers for Disease Control and Prevention.



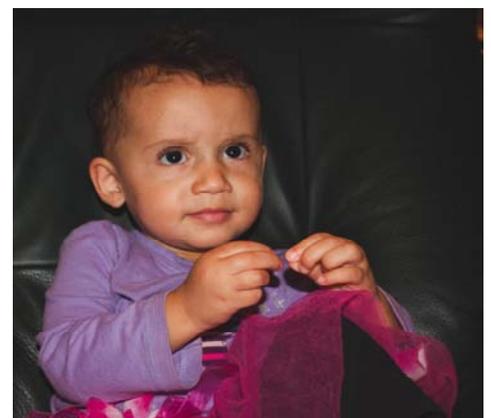
Number of Babies by Year of Birth Who did not pass and Did Not Receive Follow-Up Due to Parental Refusal

Wisconsin typically experiences only slight fluctuation from year to year among case closed reasons. However, a significant change occurred among parental refusal of follow-up in 2016. The number of cases closed as parental refusal after not passing increased from 39 cases in 2015 to 69 in 2016. For babies born out-of-hospital the increase was even greater—from 11 to 31 cases. The number of babies born at a hospital who did not pass and did not receive follow-up due to parental refusal also increased from 28 in 2015 to 38 in 2016. The number of babies who did not pass and did not receive follow-up for reasons other than parental refusal did not differ greatly between 2015 and 2016.



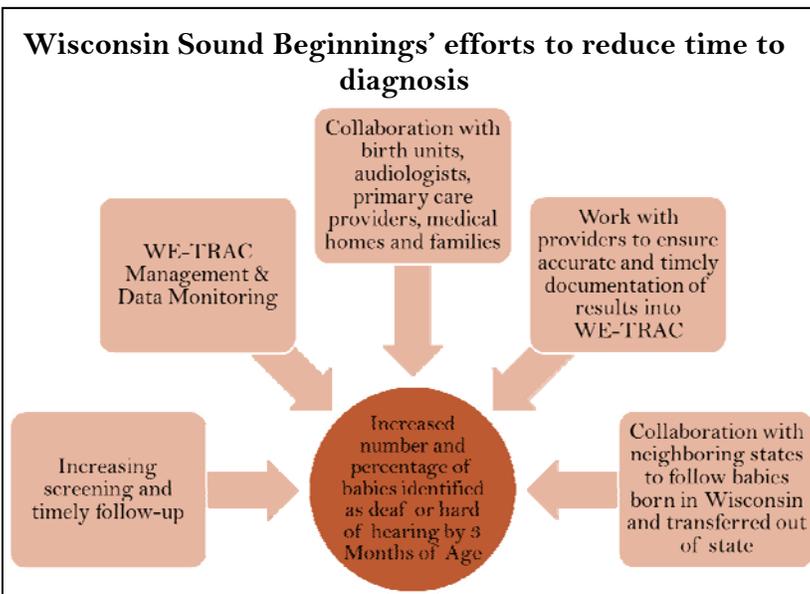
Number of Babies by Year of Birth Who Did Not Pass and Did Not Receive Follow-Up Due to Parental Refusal by Place of Birth (OOH or Hospital)

Babies who did not pass their hearing screening are at greater risk for having a permanent hearing loss than babies who passed their hearing screening. EHDI programs strive to ensure babies who did not pass receive timely follow-up. Timely follow-up is vital to ensuring babies are identified early as deaf or hard of hearing so that they can receive early intervention and parent support during the critical birth to age three period of development.



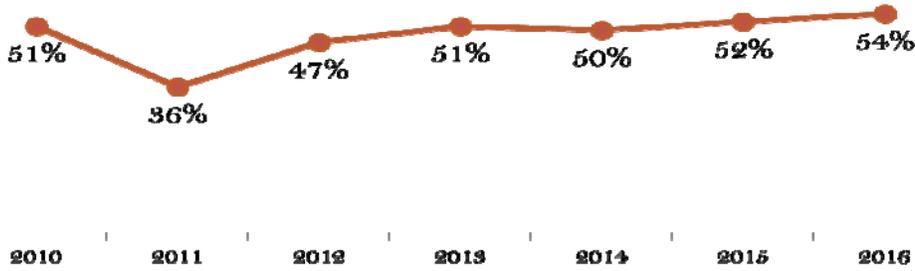


Diagnosed by 3 Months: *Reducing Time to Diagnosis and Early Intervention Referral*



Sound Beginnings' efforts to ensure newborn hearing screening and reduce LTFU for babies who did not pass both contribute to the goal of ensuring babies receive diagnostic audiology services by **3 Months of Age**.

In 2016, 54% of babies with permanent hearing loss were diagnosed by 3 Months of Age. This is the highest percentage to date.



Percentage of Babies Diagnosed with Permanent Hearing Loss by 3 Months of Age by Year of Birth

54%

of babies with Permanent Hearing Loss were diagnosed by 3 Months of Age—the most to date

Referral to Early Intervention

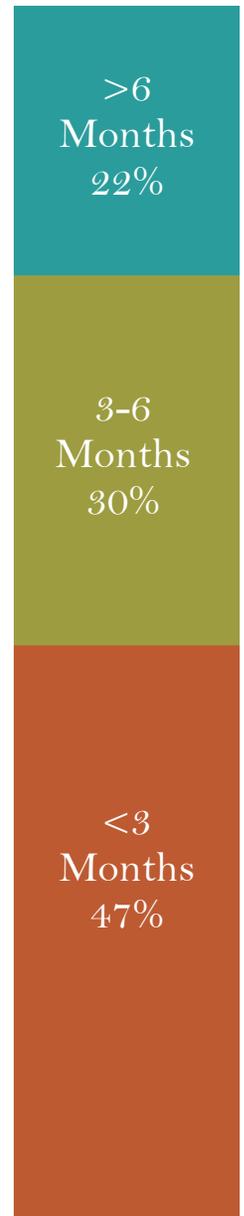
The goal of timely diagnosis is to facilitate timely referral to Part C Early Intervention. Of the 121 babies born in 2016 and diagnosed with Permanent Hearing Loss, as documented in WE-TRAC, 116 were referred to the Wisconsin Birth to 3 Program, Wisconsin’s Part C Early Intervention program. (Some babies were referred to Part C programs outside of Wisconsin.)

The age in days of a baby born in 2016, diagnosed with Permanent Hearing Loss, and referred to Part C Early Intervention ranged from just 14 days old to 442 days old.

Reasons for delays in diagnosis and referral to Part C Early Intervention included a combination of factors such as: complex medical needs; multiple screenings and/or diagnostic appointments; middle ear fluid with or without tube placement; neonatal intensive care unit stay and/or prematurity; appointments at more than one audiology clinic; and families canceling or not showing up for appointments.



Four babies passed their hearing screening and were later diagnosed with Permanent Hearing Loss (this is comparable to 2014 and 2015).

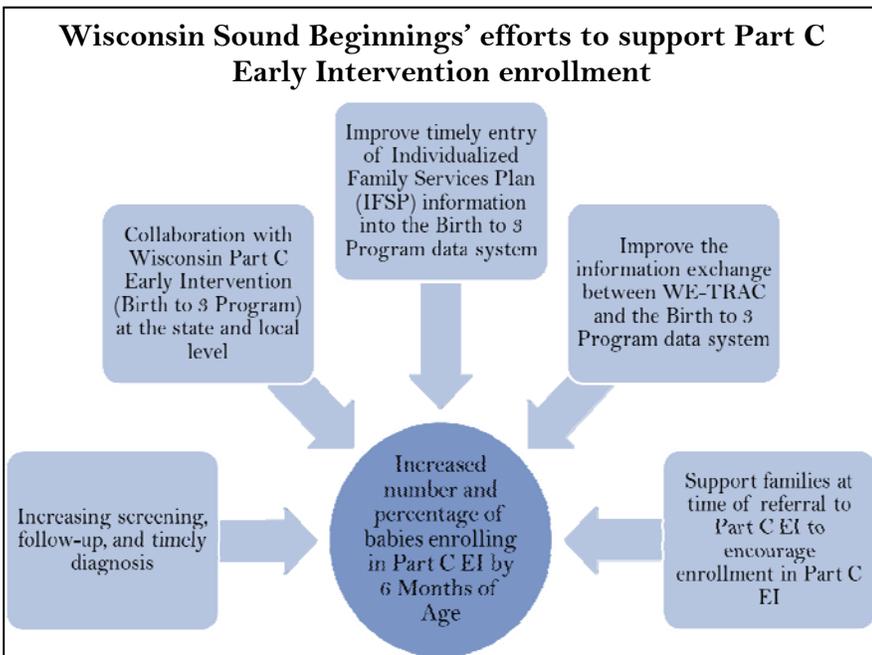


Age at Time of Referral to Part C Early Intervention



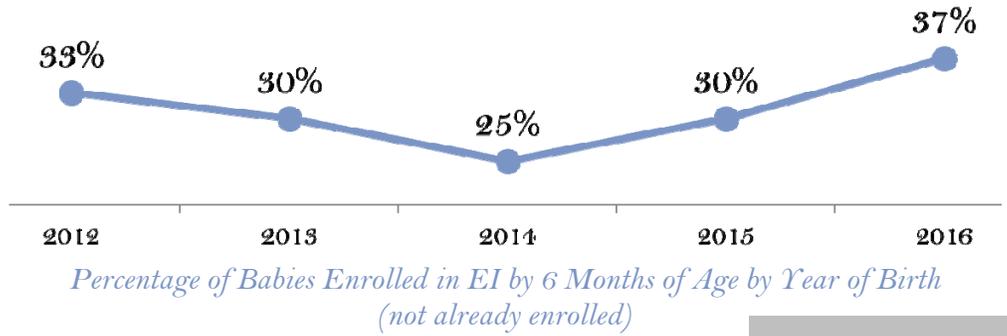
Early Intervention by 6 Months:

Enrollment in Part C Early Intervention (EI)



The ultimate goal of newborn hearing screening, follow-up, diagnosis, and referral to Early Intervention is to support positive outcomes for children who are deaf or hard of hearing.

Sound Beginnings and its partners work together to both increase enrollment and increase timely enrollment by **6 Months of Age**. Sound Beginnings and Wisconsin's Part C Early Intervention, the Birth to 3 Program, work together to support both providers and families.



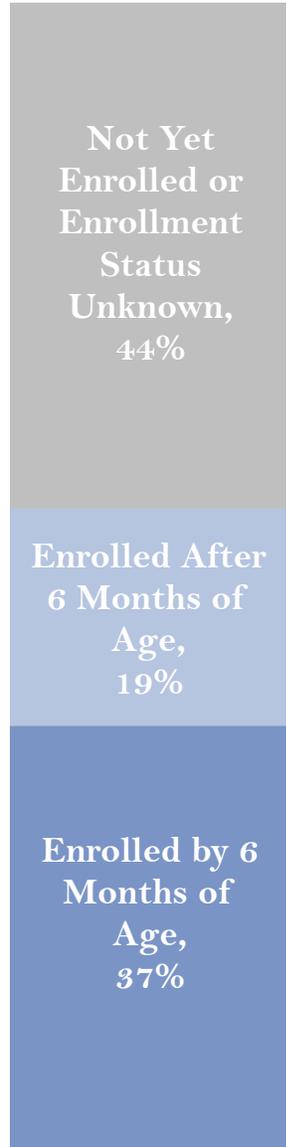
Babies enrolling in Early Intervention naturally fall into two categories: babies *already enrolled* (babies with an IFSP date that pre-dates their Permanent Hearing Loss diagnosis and WE-TRAC Early Intervention referral) and babies *not already enrolled* at the time of diagnosis and referral. Sound Beginnings focuses its evaluation of Early Intervention enrollment on babies *not already enrolled* because it provides the opportunity to better analyze Sound Beginnings' efforts to increase enrollment and timely enrollment.

Sound Beginnings receives IFSP dates and non-enrollment information from the Birth to 3 Program's data system. In 2016, 116 babies were diagnosed with Permanent Hearing Loss and referred to Wisconsin Part C Early Intervention. Of the 116 babies, 13 were *already enrolled* and had an IFSP that pre-dated their Permanent Hearing Loss diagnosis and Early Intervention referral via WE-TRAC.

37%
of babies enrolled
in Part C by 6
Months of Age;
the highest to date

not already enrolled babies enrolled in Part C Early Intervention (56%) at any point.

There were 103 babies who were *not already enrolled* in Early Intervention. Of these *not already enrolled* babies, 37% (38 babies) enrolled in Early Intervention by 6 Months of Age. A total of 58 of the



Percent Enrollment
by Age
(not already enrolled)
N=103

Early Intervention Enrollment

In Wisconsin, Permanent Hearing Loss is included in the list of conditions that allow children to be found eligible for Part C Early Intervention services due to diagnosis, regardless of whether the child is demonstrating developmental delays at the time of referral. Families may enroll at the time of referral or at any point until the child turns three. Part C Early Intervention is a voluntary program and families consent to participate.



Supporting Early Intervention and Improving Outcomes

Sound Beginnings works to increase enrollment, increase enrollment at the time of referral to Part C Early Intervention, increase duration of enrollment, and improve developmental outcomes for children who are deaf or hard of hearing.

Sound Beginnings supports Early Intervention in a variety of ways. One way is with its CARES initiative—*Coordination, Assessment, Resources and Evaluation Services*. Launched in late 2014, the first CARES Specialist serves Wisconsin's Southern Region; in 2016 a second CARES Specialist served the Northeastern Region.

CARES Specialists:

- Provide specialized knowledge and skills related to pediatric hearing loss to Birth to 3 Programs and families.
- Participate in intake, evaluation, IFSP meetings, joint visits with the primary Birth to 3 Program providers and families, and/or transition support when children turn three.
- Support families in conjunction with the family's primary Birth to 3 Program provider.

In 2016, the two CARES Specialists:

- Worked with 66 different families.
- Worked with children ranging in age from a few months old to three years.
- Attended 15 initial intake visits for children newly referred in 2016 (regardless of year of birth).
- Attended 52 evaluation and/or IFSP meetings for children enrolled in Part C Early Intervention in 2016 (regardless of year of birth).
- Completed numerous joint visits with each family and their primary Birth to 3 Program provider.
- Provided ongoing support for programs and all of the families enrolled in Part C Early Intervention in the Southern and Northeastern regions.
- Supported Birth to 3 Programs and families with transition out of Part C Early Intervention at age three.

66

families received
specialized early
intervention
support



For regions without a CARES specialist, Sound Beginnings still supported local Birth to 3 Programs. Sound Beginnings staff provided specialized knowledge and skills related to pediatric hearing loss, but did not provide direct support to families. In 2016, Sound Beginnings provided support, resources, and information to counties receiving an Early Intervention referral via WE-TRAC.

20

different counties received Sound Beginnings support for the 74 referrals they received via



Assessment of Early Intervention Outcomes (AEIOu): Since 2009, Wisconsin families with children who were deaf or hard of hearing were eligible to participate in the research project AEIOu, part of the National Early Childhood Assessment Project. Families participated when children were 13-20 months old and 30-38 months old. The research goal was to analyze participating children's communication, social-emotional, and general development; the early intervention they receive; and other variables that may affect their developmental outcomes. Sound Beginnings staff invited families to participate in the study during a Sound Beginnings outreach call when children were 14 months old. During the outreach call, Sound Beginnings also provided information about resources (for example Wisconsin Families for Hands & Voices; Deaf Mentor Program; Babies and Hearing Loss Notebook; upcoming conferences and social events; and the Children and Youth with Special Health Care Needs Regional Centers). For families not receiving Birth to 3 Program services at the time of the call, Sound Beginnings staff provided Birth to 3 Program contact information and encouraged families to contact their local Birth to 3 Program or facilitated a new referral for the family to the Birth to 3 Program. Of families eligible and interested in participating in AEIOu, 119 completed Phase 1 and 70 completed both Phases to date. AEIOu recruitment ended in April 2017. Efforts now focus on ensuring complete data and data analysis. Wisconsin is currently implementing a Phase 3 reading readiness assessment.

Wisconsin Sound Beginnings Future Directions

Wisconsin's EHDI program, like EHDI programs throughout the United States and territories, is funded partially through the federal Health Resources & Services Administration (HRSA) EHDI grant. EHDI programs receiving HRSA funding have their work guided by federal grant requirements.

In 2017, the federal grant shifted the focus of EHDI program funding towards diagnosis and early intervention, specifically focusing on parent-to-parent support for families and their children identified as deaf or hard of hearing. This is a change from previous years when the focus was on increasing screening and reducing LTFU. This shift directs Sound Beginnings resources toward engaging families in the EHDI system and offering parent-to-parent support starting at the time of diagnosis until the child turns three.

Sound Beginnings will continue to serve as a safety net for providers and families involved in the EHDI system from screening to diagnosis and early intervention, while also designing, implementing, and evaluating several new initiatives to support families and their children who are deaf or hard of hearing.



Report Definitions

Term	Definition
Baby	The term “baby” is used in this report to encompass all children involved in EHDI from birth to age three.
Birth to 3 Program	Wisconsin’s Part C Early Intervention program. This term is used interchangeably with Part C Early Intervention or EI in this report.
Complete Case	Cases where the baby has received complete follow-up. Complete follow-up includes: passing a screening or re-screening, within normal limits diagnostic result or confirmed permanent hearing loss and Early Intervention referral.
DNP	Did Not Pass: babies who received a newborn hearing screening, but did not pass it (also sometimes called “referred” or “referring” the hearing screening).
EHDI	Early Hearing Detection and Intervention
Enrolled in Early Intervention	Enrolled/Enrollment in Part C Early Intervention/Birth to 3 Program: a baby with an Individualized Family Service Plan (IFSP) date documented in WE-TRAC.
Incomplete case	Cases where a baby who did not pass has not received necessary follow-up (reasons may vary); also sometimes called generally “lost to follow-up.”
LTFU	Loss/Lost to Follow-Up: This is both a specific category for a baby who has not received follow-up and used as a general or generic term. LTFU is a reason for a case being closed in WE-TRAC and is defined as “no contact information has been found for the family.” LTFU is also used as a general or generic term referring to all babies who have not received follow-up (for example the LTFU Rate) regardless of their documented reason for not receiving follow-up.
LTFU Rate	A percentage derived from ‘the number of babies who did not pass their initial hearing screening and did not receive follow-up (not including deceased)’ divided by ‘the total number of babies who did not pass their initial hearing screening.’ In this case, LTFU encompasses all reasons a child did not receive follow-up (except for deceased), not just those for whom no contact information has been found. This percentage is not universally calculated the same across EHDI programs.
Never Screened	A baby who has not received newborn hearing screening or any type of hearing testing; has not engaged in the EHDI continuum of care.
Not Yet Enrolled in Early Intervention	A baby referred to Part C Early Intervention who does not have an IFSP date but does have a documented reason for not enrolling. Since the child has until they turn three to participate in Part C EI, they have the potential to enroll up until their third birthday.
Part C Early Intervention (EI)	Early intervention provided for children from birth to age three years old as part of the federal Individuals with Disabilities Education Act (IDEA) designed to serve infants and toddlers with disabilities, established developmental delays and/or diagnosed conditions with a high probability of resulting in a developmental delay.
PHL	Permanent Hearing Loss; a diagnosis of hearing loss of any degree that is permanent.
Still Active Case	Cases where the baby is still in the process of receiving follow-up (is not closed).
WE-TRAC	Wisconsin EHDI-Tracking Referral And Coordination: Wisconsin’s EHDI data system for hearing screening, diagnostic, and Early Intervention information.

This program is funded in part by grants from the Maternal & Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services.

Wisconsin Department of Health Services Program for Children and Youth with Special Health Care Needs
Wisconsin Sound Beginnings



State of Wisconsin
Department of Health Services
Division of Public Health
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